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A Simple and Practical Index to Measure Dementia-Related Quality of Life

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ABSTRACT

Background: Research on new treatments for dementia is gaining pace worldwide in an effort to alleviate this growing health care problem. The optimal evaluation of such interventions, however, calls for a practical and credible patient-reported outcome measure. **Objectives:** To describe the refinement of the Dementia Quality-of-life Instrument (DQI) and present its revised version. **Methods:** A prototype of the DQI was adapted to cover a broader range of health-related quality of life (HRQOL) and to improve consistency in the descriptions of its domains. A valuation study was then conducted to assign meaningful numbers to all DQI health states. Pairs of DQI states were presented to a sample of professionals working with people with dementia and a representative sample of the Dutch population. They had to repeatedly select the best DQI state, and their responses were statistically modeled to obtain values for each health state. **Results:** In total, 207 professionals working with people with dementia and 631 members of the general population completed

the paired comparison tasks. Statistically significant differences between the two samples were found for the domains of social functioning, mood, and memory. Severe problems with physical health and severe memory problems were deemed most important by the general population. In contrast, severe mood problems were considered most important by professionals working with people with dementia. **Discussion:** The DQI is a simple and feasible measurement instrument that expresses the overall HRQOL of people suffering from dementia in a single meaningful number. Current results suggest that revisiting the discussion of using values from the general population might be warranted in the dementia context.

Keywords: dementia, health-state valuation, health states, quality-adjusted life-years, quality of life.

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Introduction

Dementia has a major impact on health-related quality of life (HRQOL), and its prevalence is expected to double or triple by 2050 [1,2]. Because of this rapid increase and the poor prospects of a cure in the near future, some governments now seek to keep people in the community as long as possible. Currently, many interventions are directed to the anti-amyloid or other pathways [3]. These trials, however, rarely use HRQOL as an outcome measure, even though maintaining or improving HRQOL is a primary goal in dementia care. In light of the current perspective, the innovative HRQOL measures [4] described in this article may give impetus to intervention (both pharmacological and psychosocial) studies with societal benefits.

Preference-based HRQOL instruments that enable the generic expression of the quality of patients' health status in a single standardized value (index) are increasingly important because these are most often used to evaluate the cost-effectiveness of interventions. Generic index instruments such as the EuroQol-5D (EQ-5D) [5], the Short-Form 6-D (SF-6D) [6], and the Health Utility Index (HUI) are already available for this purpose [7]. In the field

of dementia, however, clinicians and researchers generally discredit the use of generic HRQOL index instruments because these do not specifically concern the most relevant domains affected by the disease [8–10]. The general objection is that their results are insufficiently valid. Instead, researchers suggest the use of disease-specific index instruments [11], which focus on the most relevant health domains affected by a certain disease.

All HRQOL index instruments apply valuation techniques to arrive at single HRQOL values (variously called utilities, weights, or indices) for all the health states that can be defined by these instruments. Basically, HRQOL index instruments comprise a predetermined and fixed set of health domains, each with levels that indicate the seriousness of these domains. Together that set of domains constitutes the classification system of a particular instrument. Each possible combination of domain levels is assigned a metric value expressing the overall value of a health state, which comprises the valuation stage. In this part of the task, the respondents have to assess the overall descriptions of health states instead of working through the list domain by domain (or item by item), the latter being standard procedure in descriptive HRQOL questionnaires.

Conflict of interest: The authors have indicated that they have no conflicts of interest with regard to the content of this article.

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Any HRQOL index instrument should be based on a limited set of key domains because respondents can process only a small amount of information simultaneously. As empirical studies show (and theories underpin this), a limited set of key domains may be sufficient to describe the overall HRQOL [12,13]. It is crucial to include only the most important and relevant health domains in the HRQOL index instrument. Including non-key domains might increase the content marginally but increase the difficulty of the assessment tasks substantially.

In this article, we describe the refinement of a prototype dementia-specific HRQOL index instrument specifically designed for community-dwelling people with dementia, the Dementia Quality-of-life Instrument (DQI). In previous work, we have discussed the theoretical models of HRQOL in dementia [14], discussed the need for a new instrument, and focused on the psychometric properties [15]. In this article, we focus on the derivation of health-state values, not on the psychometric properties of the DQI. Furthermore, we demonstrate how to apply this novel instrument.

Methods

Instrument

The DQI describes dementia-specific HRQOL in six domains: 1) physical health, 2) self-care, 3) memory, 4) social functioning, 5) mood, and 6) orientation. To facilitate rating, each domain consists of a limited number of levels: 1) no problems, 2) some problems, and 3) severe problems. The DQI is intended for use in community-dwelling patients. Given this number of six domains with three levels each, a total of 3⁶ (729) health states can be created. Each health state can be classified by a six-digit code consisting of one digit per domain (Fig. 1).

The final DQI differs from its prototype [15] in several ways. The prototype was restricted to five domains because the feasibility of five domains had been found acceptable for people with dementia as well as their caregivers [16]. In the AD Euro study [17], the DQI prototype showed a similar level of feasibility among people with dementia and their caregivers [18]. In addition, the EuroQol five-dimensional questionnaire with the cognitive dimension [19] has been used to measure the HRQOL in people with dementia and their proxies. That study suggested that it may be feasible to allow for a sixth DQI domain. The refinement of the prototype was based on unpublished data [20] that takes into account expert opinion, a literature review, and an additional empirical study, which indicated that professionals working with people with dementia regarded physical health as the most relevant domain of HRQOL. Therefore, this domain was added to the classification system. The new selection of domains allowed a broader coverage of HRQOL. In addition, the prototype underwent minor changes to improve consistency and uniformity throughout the domains and levels. The current selection of domains makes the DQI suitable for community-dwelling people with dementia because all domains are considered relevant for such people. We do caution about implementation in other populations because this might decrease the content validity.

Health-State Assessment

Conventionally, values for health states are derived from members of the general population [21]. Respondents who evaluate hypothetical health states, however, might not be familiar with dementia. It seems reasonable to assume that healthy people have insufficient information or imagination to make a valid judgment about the impact of dementia in its various stages [22,23]. The best judges of a health state are presumably those who have actually experienced it. In the case of dementia,

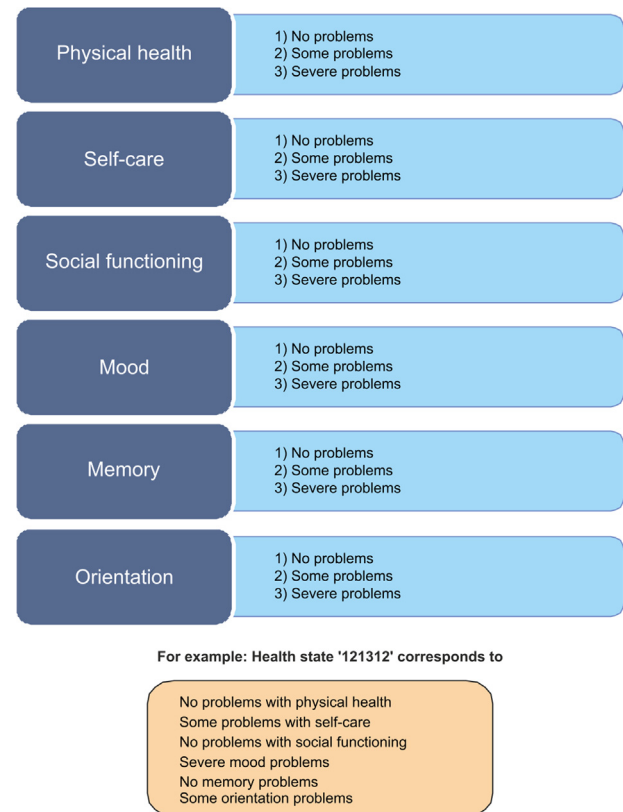


Fig. 1 – The Dementia Quality of Life Instrument. (Color version of figure is available online.)

however, their judgments about their own health state are probably biased because of their loss of insight. An alternative would be to question informal caregivers or professionals working with people with dementia because both groups have regular contact with people with dementia and are familiar with its impact on HRQOL. For this reason, the present study investigates values derived from professionals working with people with dementia and laypersons. On the basis of the literature [22,23], we hypothesized that it would be likely for the judgments of these two groups to differ substantially, in which case we would advocate using the values of the professionals.

Respondents from the professional panel and the general population were repeatedly presented with two health states (paired comparisons) and asked to indicate which one they preferred. The DQI classification system allows for 729 health states, which makes it impractical to conduct a valuation study in which all states are assessed (full factorial design). Instead, a near-orthogonal main effects design was generated (Sawtooth software, complete enumeration option) to meet certain methodological criteria (minimal overlap, level balance, and orthogonality) [24,25]. This orthogonal design allowed the estimation of main effects independent of one another. All presentations of health states (paired comparisons) were randomized while the order of domains was kept constant.

The designs also contained some paired comparisons (~4%) in which one of the two health states was dominant. A dominant comparison means that one health state was equal to or less severe on each of the domains compared with the other health state. Such comparisons served as a validity check; the number of “wrong” answers on such tasks indicates how well the respondents paid attention and understood the paired comparison task.

The survey started with demographic questions (e.g., age, sex, and location). Respondents were also asked about their

experience with severe disease (such as dementia)—whether they had experienced it themselves, in family members, or by providing care for others. The “dementia” label, however, was not used because we did not want to incur stereotyping of health states later on in the experiment. They were subsequently instructed on the definitions of the problems covered by the domains of the DQI (see Appendix A in Supplemental Materials found at <http://dx.doi.org/10.1016/j.jval.2015.07.011>) and then on the paired comparison tasks. Afterwards, the instrument’s feasibility was assessed by presenting the respondents with four statements: 1) The instructions made it clear what was expected of me; 2) It was easy to distinguish the health states that I had to compare; 3) I found it difficult to make a choice between the health states; and 4) The questions were easy to understand. Each of these statements had to be answered on a five-point scale ranging from “strongly agree” to “strongly disagree.” Overall feasibility was expressed as the percentage of respondents using the categories “strongly agree” and “agree.”

Analyses

This study is couched in a framework of modern probabilistic discrete choice theory [26–28] to ascertain the relative merit of health states. A well-established member of this class of choice models (conditional fixed-effects logit model; clogit command in STATA, version 10) was applied to estimate the weights of the domain levels. Before analysis, the domain levels were dummy coded. A separate analysis was performed on the dominant tasks as a quality check.

Our aim was to demonstrate that DQI health-state values can be used to compute quality-adjusted life-years. To do so, we have to calibrate these values on the “dead–full health scale.” This calibration task is presented in Appendix B in Supplemental Materials found at <http://dx.doi.org/10.1016/j.jval.2015.07.011>. The “Results” section will display the conditional fixed-effects logit model estimates rescaled to the “dead–full health scale.”

To investigate whether professionals working with people with dementia and laypeople interpreted dementia health states similarly, domain-level weights were compared across the two samples. This required combining the samples and estimating a new model

that included the interaction terms between each of the domain levels and a dummy variable to indicate the sample. A significant interaction term would imply that there are differences between professionals working with people with dementia and laypeople.

Respondents

A convenience sample was drawn among professionals working in the field of dementia, who were then invited to participate in an online survey for the valuation study. They were contacted via the Dutch national society of clinical geriatricians, the society for elderly care specialists (working in long-term care facilities), the Dutch institution for mental health care and addiction treatment, and professionals working with patients with dementia at the Radboud University Medical Center, Nijmegen, and the Slingeland Hospital, Doetinchem, all in The Netherlands. Their professions included the following: clinical geriatricians, elderly care physicians, nurses, social workers, researchers, psychologists, case managers, and (physical) therapists. No inclusion or exclusion criteria were used for this sample.

In addition, a market research company (Survey Sampling International, Rotterdam) recruited members of the general population. They were selected from this company’s respondent panel. Quota sampling ($n = 600$) was used to recruit respondents aged 18 to 75 years who were representative of the Dutch population with regard to age, sex, geographical area, and education. They were invited by e-mail and redirected to an online survey. Data collection took place from April to June 2012.

Results

Respondents

The paired comparison tasks were completed by 207 professionals working with people with dementia and 631 respondents from the general population. The latter sample was representative of the Dutch general population in terms of age, sex, and education (Table 1). Professionals on average had a higher

Table 1 – Sample characteristics (Dutch population values displayed as a reference).

Characteristic	Professional sample, n (%)	General sample, n (%) [*]	Dutch population, % [†]
Age (y)			
18–24	0 (0.0)	75 (11.9)	11.7
25–34	61 (29.5)	136 (21.6)	21.3
35–44	55 (26.6)	141 (22.4)	22.3
45–54	57 (27.5)	123 (19.5)	20.2
55–64	34 (16.4)	109 (17.3)	24.5 [‡]
65–74	0 (0.0)	47 (7.5)	
Sex			
Male	55 (26.6)	310 (49.1)	49.9
Female	152 (73.4)	321 (50.9)	50.2
Education			
Low	1 (0.5)	208 (33.0)	34.3
Middle	13 (6.3)	270 (42.8)	42.1
High	193 (93.2)	153 (24.3)	23.5
Experience with severe disease			
Personal	22 (10.6)	144 (22.8)	–
In family	159 (76.8)	436 (69.1)	–
By caring for others	144 (69.6)	189 (30.0)	–

^{*} Differences between the general sample and the Dutch population tested with a χ^2 test resulted in P values of >0.1 for all age, sex, and education categories.

[†] Data based on Statistics Netherlands (www.cbs.nl). Situation in 2011.

[‡] 55 y and older.

Table 2 – Feasibility of the discrete choice experiment in comparing health states as evaluated by professionals working with people with dementia and general population sample (responses in % per category).

Sample	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Professionals working with people with dementia (n = 207)					
The instructions made it clear what was expected of me	45.4	49.3	2.9	2.4	0.0
It was easy to distinguish the health states that I had to compare	6.8	26.6	23.7	30.4	12.6
I found it difficult to make a choice between the health states	26.6	51.2	13.0	6.8	2.4
The questions were easy to understand	29.0	56.5	8.2	4.3	1.9
General population (n = 631)					
The instructions made it clear what was expected of me	27.3	47.7	17.9	3.5	3.6
It was easy to distinguish the health states that I had to compare	9.7	35.2	31.9	17.4	5.9
I found it difficult to make a choice between the health states	23.1	36.0	23.8	13.0	4.1
The questions were easy to understand	27.6	46.3	18.9	4.3	3.0

Table 3 – Weights (β values) given to the different domain levels of the Dementia Quality-of-life Instrument.

Domain levels*	Professionals working with people with dementia ^{†‡} (n = 207)			General population ^{†§} (n = 631)		
	β	SE	P	β	SE	P
Some problems with physical health (2)	-0.011	0.012	0.419	-0.048	0.009	0.000
Severe problems with physical health (3)	-0.150	0.013	0.000	-0.223	0.010	0.000
Some problems with self-care (2)	-0.045	0.012	0.001	-0.059	0.009	0.000
Severe problems with self-care (3)	-0.121	0.013	0.000	-0.195	0.010	0.000
Some problems with social functioning (2)	-0.029	0.012	0.028	-0.046	0.009	0.000
Severe problems with social functioning (3)	-0.154	0.013	0.000	-0.162	0.010	0.000
Some mood problems (2)	-0.071	0.012	0.000	-0.035	0.009	0.000
Severe mood problems (3)	-0.343	0.015	0.000	-0.165	0.010	0.000
Some memory problems (2)	-0.060	0.012	0.000	-0.065	0.009	0.000
Severe memory problems (3)	-0.234	0.015	0.000	-0.225	0.011	0.000
Some orientation problems (2)	-0.021	0.014	0.178	-0.022	0.011	0.035
Severe orientation problems (3)	-0.101	0.015	0.000	-0.133	0.011	0.000

* Note that level 1 problems indicate “no problems” and therefore do not lead to a diminished health-related quality of life.

† This model is rescaled to the dead-full health scale.

‡ Pseudo $R^2 = 0.41$.

§ Pseudo $R^2 = 0.19$.

education, were more likely to be women, and had more experience with severe diseases.

Sample Quality and Feasibility

In the paired comparison tasks, professionals working with people with dementia selected 97 out of 98 dominant comparisons, indicating that 99% of the comparisons were correctly understood. In total, 387 dominant paired comparison tasks were performed by the general population sample. In 350 of these, the dominant option was indeed selected, indicating that 90% of the comparisons were correct. The difference between the laypersons and the professionals working with people with dementia was statistically significant ($\chi^2 = 7.898$; $P < 0.01$). The feasibility was considered acceptable by 63.2% of the lay people and 72.9% of the professionals working with people with dementia (Table 2).

Domain-Level Weights

Professionals working with people with dementia attached the highest weight (i.e., burden) to severe mood problems (Table 3). In contrast, the general population attached the highest weight to severe problems with physical health and severe memory problems. Four domain levels were statistically significantly judged as

Domains	Scores	Level of problems	Weights	Computation procedure
Physical health	1	2 <input checked="" type="checkbox"/> 3 <input checked="" type="checkbox"/>	0.01 0.15	0.01 0.15
Self-care	2	2 <input checked="" type="checkbox"/> 3 <input checked="" type="checkbox"/>	0.05 0.12	0.05 0.12
Social functioning	1	2 <input checked="" type="checkbox"/> 3 <input checked="" type="checkbox"/>	0.03 0.15	0.03 0.15
Mood	3	2 <input checked="" type="checkbox"/> 3 <input checked="" type="checkbox"/>	0.07 0.34	0.07 0.34
Memory	1	2 <input checked="" type="checkbox"/> 3 <input checked="" type="checkbox"/>	0.06 0.23	0.06 0.23
Orientation	2	2 <input checked="" type="checkbox"/> 3 <input checked="" type="checkbox"/>	0.02 0.10	0.02 0.10
				0.41 Sum
DQI health-state value = 1 - Sum = 1 - 0.41 = 0.59				

Fig. 2 – DQI health-state value calculation example for the DQI state “121312” using the (rounded up) values from professionals working with people with dementia (note that level 1 problems indicate “no problems” and therefore do not lead to a diminished HRQOL). DQI, Dementia Quality of Life Instrument; HRQOL, health-related quality of life. (Color version of figure is available online.)

more important by professionals working with people with dementia, namely, “severe problems with social functioning,” “some mood problems,” “severe mood problems,” and “severe memory problems” (all $P < 0.001$). All other interaction effects were not statistically significant (all $P > 0.1$). The DQI health-state values can simply be calculated as displayed in Figure 2. They range from 1 to −0.103 (see Appendix B).

Discussion

The present study reports on the domain selection and valuation outcomes of the DQI. Clear differences were observed between the two samples. Professionals working with people with dementia attached higher values to “mood problems,” “social functioning,” and “memory problems” than did members of the general population. Apart from these differences, the responses of the professionals showed better performance. On the basis of these two findings and in light of studies showing that the general population is inadequately informed about dementia [22,23], we recommend revisiting the debate on using values derived from professionals (as opposed to the general population) in the field of dementia.

The differences between the two samples may be explained by the fact that laypeople are less able to imagine what dementia is like than professionals because professionals regularly come into contact with people who actually live with this condition. By implication, almost all the currently used HRQOL index instruments might be producing suboptimal or even invalid health-state values. Many studies have investigated the potential differences in valuing health states between the general population and people who actually experience illness (see De Wit et al. [29] for an overview). Some authors have attributed these differences to the measurement method used [30]. Differences in methodology (e.g., selection of health domains, valuation methods), however, do not explain the differences in values between professionals working with people with dementia and laypeople in the present study. Guidelines on cost-effectiveness research in health recommend using values representative of the general population [21].

Given the paucity of general knowledge about dementia, however, the better performance on dominance checks by the professionals, and the results for model performance reported here, we recommend revisiting the discussion of using values from sources other than the general population.

The current instrument was developed in The Netherlands; one might wonder whether the values of the DQI are equally valid elsewhere. Research on generic index instruments reveals slight systematic differences in health-state values between most countries [31,32]. Such differences can arise because of variations in the valuation methodology, translational issues, and (cultural) specificities in each population’s preferences for health states and health domains. We believe that the DQI in its present state can be used in other countries if researchers are aware that the values for the DQI states may be somewhat less precise. A better approach would be to properly translate the DQI for each country [32] and then conduct a separate valuation study to derive country-specific values.

The valuation study of the DQI was performed by means of an online survey. This made it easy to contact potential respondents, and the online interview costs were substantially lower than those of holding personal interviews. A disadvantage is the difficulty in assessing the credibility of respondents’ answers. To compensate for this, respondents were presented with dominant paired comparisons, which gave the researchers some indication of the validity of the responses. Professionals working with people with dementia answered 99% of the dominant choice tasks correctly. For the general population,

this was only 90%, meaning that some of the paired comparison tasks were filled in erroneously or at random. One great advantage of the valuation methodology applied here is that choosing one of the two DQI health states at random will generate noise in the data (and thus increase the standard errors of the domain-level weights) but will not affect the size and direction of the domain-level weights. In view of this advantage, it was decided not to eliminate responses of respondents who failed this “dominance test.” Moreover, a recent study also based on the paired comparison task [33] found no differences in the valuation of health states between face-to-face interviews and online administration, suggesting that both modes are equally valid.

The present study has some limitations as well. Caregivers are often with patients with dementia 24/7 and potentially are better judges of a health state than is a professional who might see the patient for a brief window of time at intervals. Using caregivers in addition to respondents from the general population and professionals working with people with dementia would yield additional interesting findings in the assignment of health-state values to the DQI. A second limitation is that with the addition of the physical health domain, and alterations to descriptions of other domains and levels, the previous study supporting the validity of the DQI [15] may not be completely relevant anymore. Ideally, new studies should be undertaken to again demonstrate the validity and reliability of the DQI. The developers of the DQI plan to address both the above-mentioned limitations in future studies. The authors recommend not using the prototype of the DQI anymore because that instrument does not have values for each of the health states it classifies.

Finally, because of the sampling strategy of using a convenience sample, our sample might not be perfectly representative of professionals in the field of dementia. Results might be biased by the fact that our respondents are more likely to be proactive, participate in online questionnaires, and willing to aid colleagues.

Another new set of dementia-specific HRQOL index instruments has recently been developed [34], called DEMQOL-U and DEMQOL-Proxy-U. Although initially considered a step forward in the valuation of dementia-specific HRQOL, these instruments have since been criticized, citing a supposed absence of important HRQOL domains and the application of suboptimal methodologies [35]. Specifically, the absence of a domain that focuses on the physical part of HRQOL was considered to be a major limitation. An important direction for future research would be to compare the DQI, DEMQOL-U, and DEMQOL-Proxy-U with generic preference-based instruments such as the EQ-5D, HUI-3, and SF-6D with respect to their application for economic evaluations, clinical monitoring, and disease modeling studies on community-dwelling people with dementia.

In conclusion, the development of the DQI is an important step forward in expressing the level of HRQOL among the rapidly increasing population of community-dwelling people with dementia in a single meaningful number. The DQI overcomes the shortcomings in content and scope of generic HRQOL index instruments and provides a feasible and relevant patient-reported outcome measure.

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Supplemental Materials

Supplemental material accompanying this article can be found in the online version as a hyperlink at <http://dx.doi.org/10.1016/j.jval.2015.07.011> or, if a hard copy of article, at www.valueinhealthjournal.com/issues (select volume, issue, and article).

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